

Families as Presenters

A MANUAL AND DIRECTORY

*Families of Children with Special Needs as
Higher Education Classroom Presenters in Iowa*



Iowa Department of Education
2003

State Board of Education...

State of Iowa
Department of Education
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Des Moines, Iowa 50319-0146

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Foreword...

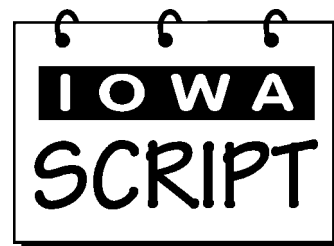
Early ACCESS and Iowa SCRIPT (Supporting Change and Reform in Interprofessional Preservice Training) offer information and resources to families and faculty willing to collaborate in preservice personnel preparation programs. These programs prepare future providers of early intervention services.

Early ACCESS is a system of partnering families and professionals who provide support, resources and early intervention services to families with infants and toddlers with special needs. It is Early ACCESS and Iowa SCRIPT's goal that all professionals will understand and use family centered practices in all aspects of their work with families.

Iowa SCRIPT is a project designed to develop, test, and evaluate an innovative model for facilitating preservice improvements. One of the project's goals is to help sponsor the "Parents as Presenters" workshops to provide training to families of children with disabilities who are interested in sharing their experiences with college classes and other audiences. Iowa SCRIPT has helped sponsor two workshops in the past two years and is continuing to provide support for future workshops.

Early ACCESS and Iowa SCRIPT believe that partnerships between families and providers are vital for a quality, family-centered system of support. Research and our experience have shown the value of families participating in all activities of our early intervention system. When families and providers work together for a common goal and build upon each other's strengths, the providers are more likely to use helping behaviors that are empowering to families. When these partnerships are modeled in pre-service training, students learn how to use family centered practices before they begin their teaching careers.

This manual provides a parent directory listing the families who have attended the two-day training and a guide for contacting and supporting these family members as resources for personnel preparation programs.



Acknowledgments...



This project came from a planning process initiated by the Iowa SCRIPT (Supporting Changes and Reform in Interprofessional Preservice Training in Iowa) team. It could not have been successful without the extensive collaboration efforts that went into planning and conducting the family training event. This involved a cadre of parents and representatives from higher education, the Parent Training Information Center of Iowa, Family Voices of Iowa, Early ACCESS, the Parent Educator Connection, and the Iowa Department of Education: Julie Curry; Susan Maude, Loras College; Shelley Ackermann; Carrie Fitzgerald, Department of Public Health; Sheila Hourigan, Mary Schertz, and Lisa Sharp.

We would also like to thank the Missouri FEEL project for providing the training curriculum.

***“There is no doubt that
I am a better teacher
having co-instructed with a parent...”***

Co-instruction heightened my awareness and sensitivity to the language that I used, the attitude that I portrayed, the generalizations that weren’t appropriate. She [parent] kept me honest!”

Dr. Susan McBride,
Iowa State University

Quotes from different perspectives....

A Student

Through the stories parents shared about their lives, I have learned a great deal more than by reading a book. It put a face and emotions on the “families” we are always talking about in our activities. It has helped me see what kind of lives parents may be living when all I otherwise would have thought about was the child. Getting to actually hear from parents helps me to better understand the purpose of being family-centered and how important it is.

A Faculty Member

The presence and contributions of parents of children with disabilities in my class is invaluable. There is nothing that I can say that can have the same impact as parents sharing their stories and personal lives with students. These stories are what make the difference in students learning what family-centered really means.

Introduction

Why a directory?

This directory is intended to help college and university faculty and others throughout Iowa identify family members of children with disabilities who are willing to share their stories. Families can be influential in shaping college students' attitudes and practices when family participation is integrated throughout college courses and experiences. When students learn the principles and practices of family-centered services in meaningful ways, they are better prepared to develop empowering relationships with families in their chosen profession.

Higher Education faculties throughout Iowa have already enhanced their curricula by inviting parents to present their perspectives to students. These faculty enthusiastically confirm the value of practice, and student feedback on course evaluations routinely provide additional support:

How were parents selected to attend the Parents as Presenters training?

In the winter of 2001, a group of parents representing different parent organizations and Iowa SCRIPT team members met to plan for the workshop. This group decided to borrow the curriculum developed for the FEEL Project (Families' Experiences Enhance Learning) that was designed by the Center for Innovations in Special Education in Missouri. The Iowa group targeted key agencies that could notify families about the availability of this training opportunity. Family members submitted applications to this group. Approximately 40 individuals were selected to attend based upon a wide representation of regions of the state, ages of children, disabilities of children, and interests and experiences of the applicants.

While the primary focus of this project is to provide training for family members who have young children, the family members of older children were not excluded. These family members can provide very relevant perspectives and expertise

that will be valuable to early intervention and early childhood practitioners.

Due to the success of the 2001 workshop for families, it was decided that another workshop would be offered in the fall of 2002. We held the workshop in September of 2002 and now have added more families' names to this directory.

How do you use this manual and directory?

We have provided some suggestions and tips when inviting family members to speak to your students or to key stakeholders. We share information on how to find family members, a continuum of roles family members can take, clarification of roles, compensation, and a list of resources. Starting on page 18, there is a listing of family members with a short description of each child's special needs, family scheduling preferences and topics of interest.

We hope this information will be useful to you. Please select a family member and contact him or her to discuss your training needs.

Finding Families for Co-Presenting



If you don't find a family in your geographic area listed in the directory, here are some other ways to find families:

- 1) Develop a partnership with local service providers who work with young children with disabilities and their families. Ask these providers to pass along a letter inviting families to come tell their stories in your class.
- 2) Contact the Early ACCESS Regional Coordi-

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nator in your area by calling your Area Education Agency.

- 3) Contact the Parent Training and Information Center of Iowa located in Des Moines at 1-800-450-8667 or 515-243-1713 or www.iowapti.org. The Center has a directory that lists parents of children with special needs who are willing to participate in parent leadership opportunities. They also have information about parent support groups throughout the state and could facilitate communication with them.
- 4) Contact the Parent – Educator Connection (PEC) representative in your local Area Education Agency (AEA).
- 5) After getting to know a family, ask them whom they know in the community that might like to present in your class. If you have some funds you could even pay a family member to help you connect with and contact other families (See SCRIPT mini grant description, page 10).

A continuum of co-instruction roles

When inviting a family member to participate in your class, it is a good idea to first agree on how and to what extent the family member will participate in the course. At one end of the continuum, parents may only visit the class once as part of a panel, whereas at the other end of the continuum, a parent comes to every class as a co-instructor. The instructor will need to know the parent's strengths and experiences to help determine the extent of the parent role (McBride, Sharp, Hains & Whitehead, 1989).

Some faculty invite several family members as guest speakers to be part of a panel. The families share their stories, and there could be a specific topic to address that corresponds with class curriculum. The family member usually gives information in the form of a family story. This can be done in a conversational manner, in response to specific questions or as a prepared presentation. To



encourage creativity, we ask families to bring pictures or props. It is also good to set aside time at the end to let students ask questions. We have found that it works best if the students have some prepared questions for the

panel in order to start the dialogue. In larger classes you may want students to write down questions during the presentation/panel and the instructor can then sort and review before giving them to guest speakers.

On the other end of the continuum, a parent participates as a co-instructor the entire semester. The parent co-instructor role varies depending on their comfort level and experience. At first the parent might only share the family perspective as the faculty member teaches content. As the parent-faculty relationship grows parent co-instructors might want to take on more responsibilities (e.g., teach course content, grade tests and papers, and contacting other family members to be involved with the course).

Over time as the partnership matures and changes, these decisions are jointly made with the parent and faculty member. This is a wonderful demonstration of the mutual learning that can occur between parent and professional.

Other preservice roles

Family members can also be involved with students without ever entering a classroom setting. A student can be matched up with an individual family for a number of visits that may include an information gathering conversation as well as an avenue for starting to begin learning how to listen to families. There are some preservice programs that assign a student to a family for an entire

semester. The student has time to really understand the family and to reciprocate to the family in some way (e.g. provide childcare, assist with tutoring, cook a meal for the family). A family might not have the time to participate in any of these roles but can be a valuable resource in helping you connecting with other families.

Family members have a wide variety of experiences. Some may be experienced public speakers, while others may be relatively new at presenting to a group. Here are some tips for inviting families:

Initial Invitation Call

- At least two weeks prior to the date invite the family member to speak to the class;
- Describe the class or inservice, the topic, and the objectives you would like the family member to address:

What is the main purpose of the class or session?

What do you hope the students will gain?

Which family centered practices are you hoping to illustrate?

What questions might the students ask the family member?

- Discuss how much time the family has to share their information/story;
- Discuss how the family and instructor will work together if things become uncomfortable or too emotional. Is this family okay with the emotions that may develop or is there something the instructor can do or say if that happens?
- Ask the family member if audiovisual equipment and/or assistance with handouts are needed;
- Discuss compensation or honorarium, how much, and when to expect payment.

Follow-Up

- Send a follow-up note to confirm the date, time, location, and parking availability; You can send a map and/or parking permit at this time if necessary;
- Consider ways in which to make the family member comfortable;
- Prepare the participants for the family member's presentation. Ask participants to think of some questions beforehand;
- Offer to arrange for a participant to meet the family member at a specific location to help guide them to the meeting room or carry materials;
- Call a day or two before the date to ask if there are any last minute questions, discuss the presentation, and finalize details.

Day of Presentation

- Provide an introduction that acknowledges the family member's expertise.
- Remind the family that she/he does not need to answer sensitive questions.
- Offer to facilitate discussion.
- Have water or a beverage available for the guest speaker
- Consider giving a small token of thanks (pen, note pad, flowers, in addition to honorarium).



After Presentation

- Send a brief thank-you note with positive comments from the participants or encourage students to directly send thank you notes (students could get extra credit points).
- Follow up with information on the honorarium.

Talking about and offering compensation



Offering supports to families when they participate in preservice training demonstrates respect for their contributions. It also models reciprocity in the relationship, a vital ingredient in effective partnerships.

Conversations about compensation: After it is clear what the family will be doing to meet the needs of the class, it is time to have a conversation about compensating the family for their time and effort. This is so families can in turn receive resources that meet their individual needs (e.g., childcare, mileage). Compensation does not have to only be monetary. Ask the families what they need or offer an array of resources. Really, anything can be negotiated until everyone feels good.

Offering resources: Early ACCESS encourages colleges and universities to find ways to offer creative resources to families in exchange for their participation. Right now Early ACCESS has some funds available for a small honorarium (see page — for details) for a one time visit to a class. However, there are not enough funds to support a full semester of co-instruction, so as faculty you will need to obtain resources through the college system. Personnel Preparation grants can be written that specifically support family/faculty co-instruction. Family members can be hired as adjunct faculty or donations from local community/civic groups can be obtained.

Other resources families may like includes:

- Respite care by students;
- Tickets to college/university or community events (e.g., sports, concerts);
- Passes to college or university recreation centers, gyms;

- Financial reimbursement;
- College course credit (in-kind);
- Community education opportunities (i.e., computer classes, art classes).

BE CREATIVE!

Funding Sources

Early ACCESS and Iowa SCRIPT Honorarium

Early ACCESS and Iowa SCRIPT have committed a sum of money within their budgets to assist faculty who invite families to present in their classrooms. The monies are intended to reimburse families for their participation in illustrating the Early ACCESS guiding principles of family centered services and practices. The honorarium for a classroom presentation is \$35 dollars. See Forms section for payment instructions.

Iowa SCRIPT Mini grants

For presentations that involve more preparation, time, or co-teaching Iowa SCRIPT offers mini grants for seed money to support family involvement in the college or university classroom. Call or email Mary Schertz at the Iowa Department of Education, 515-281-5433 or Mary.Schertz@iowa.gov

The above are just two of the funding resources that faculty can offer to families. Early ACCESS and Iowa SCRIPT are pleased to offer these resources at this time, but realize that a long-term approach to compensating families is needed. Higher education institutions will need to make efforts toward developing structures within their own system or community that offer a range of options to families for continuing support.

References

McBride, S.L. Sharp, L., Hains, A.H., & Whitehead, A. (1995). Parents as co-instructors in preservice training: A pathway to family-centered practice. *Journal of Early Intervention*, 19(4), 343–355.



Resources

Butera, G., Matuga, K., & Riley, S. (1999). Doing as we do: Guiding student development in family focused intervention using family stories and parent co-instruction, *Infant Toddler Intervention: The Transdisciplinary Journal*, 9(2), 107–121.

Bricker, D. & Widerstrom, A. (1996). Preparing personnel to work with infants and young children and their families: A team approach. Baltimore, MD: Paul Brookes.

Brinker, R.P. (1992). family involvement in early intervention: Accepting the unchangeable, changing the changeable, and knowing the difference. Topics in *Early Childhood Special Education*, 12(3), 307–332.

Capone, A.M. & DiVenere, N. (1996). The evolution of a personnel preparation program: Preparation of family-centered practitioners. *Journal of Early Intervention*, 20(3), 222–231.

Gilkerson, L. (1994). Supporting parents in leadership roles. *Zero to Three*, 14(4), 23–24.

Jeppson, E.S., & Thomas, J. (1997). Families as advisors: A training guide for collaboration. Bethesda, MD: Institute for Family-Centered Care.

Jeppson, E.S., & Thomas, J. (1995). Essential allies: Families as advisors. Bethesda, MD: Institute for Family-Centered Care.

King, S. (1994). Telling your family story... Parents as presenters. Madison, WI: Parent Projects, Wisconsin Personnel Development project, Waisman Center, University of Wisconsin-Madison.

Moss, J. (1997). Telling your story. University Affiliated Program of Oklahoma, College of Medicine, University of Oklahoma Health Sciences Center. Publication No. CA398.jm.

Poyadue, F.S. (1988). Parents as teachers of health care professionals. In *Children's Health Care* (pp. 43–45). Bethesda, MD: the Association for the Care of Children's Health.

Rosin P., Whitehead, A.D., Tuichman, L., Jesien, G.S., begun, A.L., & Irwin, L. (1996). Partnerships in family-centered care: A guide to collaborative early intervention. Baltimore: Paul Brookes.

Shelton, T.L., & Stepanek, J.S. (1994). Family-centered care for children needing specialized health and developmental services. Bethesda, MD: Association for the Care of Children's Health.

Telling Your Family Story (1994). Parent Projects. Madison, WI: Waisman Center, University of Wisconsin at Madison.

Whitehead, A., & Sontag, J.C. (1993). Co-instruction: A case study. Madison, WI: Wisconsin Personnel Development Project, Waisman Center—UAP, University of Wisconsin—Madison.

Whitehead, A. (ED.). (1994) *The parent perspective: a parent consultant directory* (2nd Ed.). Madison, WI: Wisconsin Personnel Development Project, Waisman Center, University of Wisconsin—Madison.

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- Whitehead, A., Jesien, G., & Ulanski, B.K. (1998). Weaving parents into the fabric of early intervention interdisciplinary training: How to integrate and support family involvement in training. *Infants and Young Children*, 10(3), 44–53.
- Winton, P.J. (1991). *Working with families in early intervention: an interdisciplinary preservice curriculum*. Chapel Hill, NC: Frank Porter Graham Child Development Center.
- Winton, P.J., & DiVenere, N. (1995). Family-professional partnerships in early intervention: Guidelines and strategies. *Topics in Early Childhood Special Education*, 15(3), 296–313.

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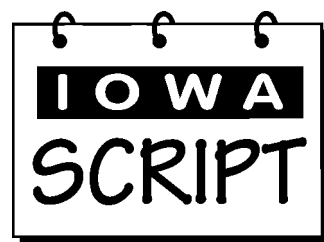


More Student Comments...

I have been so impacted by the personal stories of the families that I will never look at working with a child in the same way. I no longer have such a narrow perspective that focuses only on the child. That child is now a part of something larger, involving the whole family and so many other people. I hope that I will continue to grow in my understanding of the concept of supporting the whole family.

From the Parents...

I had no idea that what I had to say was so new for these students. I wanted them to know what it has been like for our family to get services so they can make a difference for other families. They asked wonderful questions that helped me to understand that I was really making a difference in their learning.



Instructions for Processing Application for Co-Presenting Honorarium

There are two ways to send in this application:

Make a copy of the **Application for Co-Presenting Honorarium** form, complete it and mail or FAX to:

Linnie Hanrahan
Iowa Department of Education
Grimes State Office Building, 3rd Floor
Des Moines, Iowa 50319-0146
FAX: (515) 242-6019

Complete the application form, and send through e-mail to:

Linnie Hanrahan
Linnie.Hanrahan@iowa.gov

We recommend that you cut and paste the information into the text of an e-mail message if you encounter problems with attachments.

Instructions for Requesting a Co-Presenting Honorarium:

Your request for an honorarium is processed through the Iowa Department of Education, Bureau of Children, Family and Community Services on behalf of Early ACCESS and Iowa SCRIPT.

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1. Please complete all information on the application form and submit it by mail, FAX, or e-mail twenty-five (25) working days **before** the date of co-presenting. (The paperwork process takes at least one month, so delays in submitting the form will result in payment delays for family members).

***Note to faculty:** You can facilitate this process by organizing the requests for a number of families ahead of time and sending them in as a batch.*

2. After the scheduled co-presentation, a claim voucher will be sent to the family.
3. Families are to return the signed claim voucher in the enclosed envelope for further processing.
4. A check will be issued about three (3) weeks after the office receives it.

***Note to family members** who are employees of the State of Iowa or the Regents' Programs: University of Northern Iowa, University of Iowa, Iowa State University, Iowa School for the Deaf, and Iowa Braille and Sight saving School. **We are unable to issue a check to your directly. The honorarium goes directly to your employer.** We recommend that you communicate and make appropriate arrangements with your employer regarding this activity.*

5. If a family member was unable to co-present on the scheduled day, please have the family indicate that on the claim voucher when they receive it and return the voucher in the enclosed envelope. The Department needs this information in order to cancel the claim.

Contact Linnie Hanrahan for questions about the request process at **(515) 281-3021**.

Thank you.



APPLICATION FOR CO-PRESENTING HONORARIUM

Honorarium: \$35 for one presentation that supports one class.

PLEASE NOTE: Honorariums can only be given to co-presenters of classes that prepare future service providers of young children with special needs (birth to age 8).

Today's date: _____

Information about the Co-Presenter

Name of family presenter: _____

Address: _____

Daytime Phone: _____ Nighttime Phone _____

Social Security Number: _____

State of Iowa or Regent's Program employee? _____ Yes _____ No

Ethnicity (optional): _____

Information about the Class/Instructor

Co-presenting date: _____

Name of Instructor: _____

Name and Number of Course: _____

Name of College/University: _____

E-mail address of Instructor: _____

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Students in this class are being prepared to work with children: (check all that apply)

_____ Birth to three years _____ Three to five years _____ Five to eight (K-3 grades)

Please write a one or two sentence statement about the role/purpose of family co-presenter, related to family-centered practices listed below. (e.g., *Participate on parent panel about the grieving process related to raising a child with a disability and what constitutes a “helpful” relationship (checking Family Centered Principles 2 & 3)).*

Statement: _____

Check family-centered principles* that will be highlighted during the co-presentation.

_____ Principle 1	The overriding purpose of giving family-centered help is family “empowerment,” which in turn benefits the well-being and development of the child.
_____ Principle 2	Mutual trust, respect, honesty, and open communication characterize the family-provider relationship.
_____ Principle 3	Families are active participants in all aspects of service. They are the ultimate decision-makers in the amount, type of assistance and the support they seek to use.
_____ Principle 4	The ongoing “work” between families and providers is about identifying family concerns (hopes, needs, goals or wishes), finding family strengths, and the services and supports that will provide necessary resources to meet those needs.
_____ Principle 5	Efforts are made to build upon and use families’ informal community support systems before relying solely on professional, formal, services.
_____ Principle 6	Providers across all disciplines collaborate with families to provide resources that best match what the family needs.
_____ Principle 7	Support and resources need to be flexible, individualized and responsive to the changing needs of families.
_____ Principle 8	Providers are cognizant and respectful of families’ culture, beliefs, and attitudes as they plan and carry out interventions.

*Family Centred Services: Guiding Principles and Practices for Delivery of Family Centered Services, March, 2004, Early ACCESS and Iowa SCRIPT.

FAMILY-CENTERED AND INTERDISCIPLINARY INTERVENTION FOR YOUNG CHILDREN SELF-ASSESSMENT—PRE-TEST/POST-TEST

Directions: Read each statement and circle the number on the corresponding scale that reflects your rating of your knowledge, skills, and attitudes related to working with families of children with disabilities. This rating should reflect your *current* level of knowledge or skills and your *current* attitudes. Please remember there are no right or wrong responses. You will be asked to respond to these same statements at the end of the semester to assess where the course has made the most impact on you. **Thanks for your help!**

	1	2	3	4	5
	I am a a new student to this topic		I am familiar with this topic		I could teach this topic
1. I understand the philosophy and principles of family-centered services.	1	2	3	4	5
2. I can describe parental rights and responsibilities related to IDEA, P.L. 94–192 and 99–457.	1	2	3	4	5
3. I can describe family characteristics that influence family resources and coping strategies.	1	2	3	4	5
4. I can describe the importance of informal networks of support in the health and well-being of families.	1	2	3	4	5
5. I can explain how my own cultural values might affect my work with families from diverse situations.	1	2	3	4	5
6. I can describe several strategies for involving families in their child's assessment.	1	2	3	4	5
7. I can describe several strategies for identifying family concerns, priorities, and resources.	1	2	3	4	5
8. I can describe how a child with a disability might impact all family members.	1	2	3	4	5

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	1	2	3	4	5
	I am a new student to this topic		I am familiar with this topic		I could teach this topic
9. I can describe effective components of a family-centered visit.	1	2	3	4	5

	1	2	3	4	5
	I am a beginner		I am a novice		I am an expert
10. I feel I could effectively implement family-centered practices.	1	2	3	4	5
11. I am able to listen to conversation and understand the relationship between expressed concerns and the real needs identified by the family.	1	2	3	4	5
12. I have the ability to act as a resource and assist in coordinating needed services as identified by families.	1	2	3	4	5
13. I feel comfortable assessing the skills of younger children and their interactions with their family.	1	2	3	4	5
14. I am comfortable with “role” release and can function using a variety of consulting techniques.	1	2	3	4	5
15. I could conduct a family-centered home visit.	1	2	3	4	5
16. I have skills to facilitate family members to identify and mobilize resources.	1	2	3	4	5
17. I have the skills to work in transdisciplinary teams.	1	2	3	4	5

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		1	2	3	4	5
		I do not agree at all		I am neutral		I fully agree
18.	Every family is able to make positive contributions to their child's development.	1	2	3	4	5
19.	Each family should determine to what level and extent they will participate in early intervention services.	1	2	3	4	5
20.	Intervention outcomes generated by or shared by family members are more effective than those developed by professionals.	1	2	3	4	5
21.	All families, regardless of cultural or socioeconomic status, are able to participate as equal partners in the planning of intervention goals and services.	1	2	3	4	5
22.	My personal values and biases will affect my interpretation of family resources and capabilities.	1	2	3	4	5
23.	Parents are as capable as their interventionists in identifying needs of their child.	1	2	3	4	5
24.	I believe it is ok for a family to take a break from therapy, even if I think that the child's progress may suffer.	1	2	3	4	5
25.	Professionals need families input to be realistic about the abilities of of the child with special needs.	1	2	3	4	5

